# **A Guide for Family Caregivers**





# DEPARTMENT OF CITZEN SERVICES HOWARD COUNTY, MARYLAND – OFFICE ON AGING

Ken Ulman, County Executive Susan Rosenbaum, Director Sue Vaeth, Administrator

## A GUIDE FOR FAMILY CAREGIVERS

August 2007 (7<sup>th</sup> edition)
Original edition: Diane Perry
Revised and edited by: Emily Leclercq, Valerie Liss
Designed by: Craig Gotschall

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# Howard County, Maryland - Office on Aging

6751 Columbia Gateway Driver, 2<sup>nd</sup> Floor Columbia, MD 21046 Phone: 410-313-6140 Maryland Relay: 711 TTY/Voice: 410-313-6401

Fax: 410-313-6540 Email: svaeth@howardcountymd.gov

#### **ACKNOWLEDGEMENTS**

Special thanks to: Pam Bilal, Marsha Broaddus, Donna Cookson. Jeannine Giffin, Craig Gotschall, Madeleine Greene, Stephen Hannan, Barbara Harris, Karen Hull, Dot Keczmerski, Patti Kost, Jeannette Krapcho, Phyllis Madachy, Mary Omvig, Peggy Rightnour, Lisa Sarro, Jennifer Schwartz-Mitchell, Betty Totaro, Hazel Watson, and Mary Ann Wilkinson.

This Printing: 2/09

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# I. INTRODUCTION

The staff of the Howard County Office on Aging recognizes the important role caregivers play in our community. We appreciate that the care each of you provides enriches the quality of life for another person. We know that while caregiving can be rewarding, it also can be stressful and taxing physically, emotionally and financially.

That's why we have developed this guide to provide you with information and a list of community and other resources to assist you in caregiving; we hope you will find it helpful. If you do not find what you need in our guide, or if you have questions, you may contact us at the Maryland Access Point (MAP) of Howard County at 410-313-5980. We will do what we can to help. Also, we'd like to hear from you about how we can make the guide more useful for caregivers.

If the person you care for lives outside of Howard County, perhaps in another state, you may want to contact the Eldercare Locator at 1-800-677-1116; or <a href="www.aoa.dhhs.gov">www.aoa.dhhs.gov</a> for information about other agencies that can assist you.

Keep in mind that whatever your situation, you do not have to face it alone. There are many other caregivers and a number of resources in Howard County and elsewhere that you can turn to for support. Refer to section VII for a list of community and other resources. One of these resources, the National Family Caregivers Association in Kensington, Maryland, has developed 10 tips that may be useful to you.

## **10 TIPS FOR FAMILY CAREGIVERS**

- 1. Choose to take charge of your life, and don't let your loved one's illness or disability always take center stage.
- 2. Remember to be good to yourself. Love, honor and value yourself. You're doing a very hard job and you deserve some quality time, just for you.
- 3. Watch out for signs of depression, and don't delay in getting professional help when you need it.
- 4. When people offer to help, accept the offer and suggest specific things that they can do.
- 5. Educate yourself about your loved one's condition. Information is empowering.
- 6. There's a difference between caring and doing. Be open to technologies and ideas that promote your loved one's independence.
- 7. Trust your instincts. Most of the time they'll lead you in the right direction.
- 8. Grieve for your losses, and then allow yourself to dream new dreams.
- 9. Stand up for your rights as a caregiver and a citizen.
- 10. Seek support from other caregivers. There is great strength in knowing you are not alone.

# II. CAREGIVER PROFILE

# WHO ARE THE CAREGIVERS?



If you are reading this handbook, chances are you're already a member of the more than 22.4 million households involved in caregiving. If you provide care for another person with a chronic condition that impairs his/her ability to function independently, you are a caregiver. As a caregiver, you may be a relative, friend, neighbor, companion, volunteer, professional (e.g., nurse, social worker, doctor, member of the clergy), church parishioner, or other member of the community providing care to a person at home or in an institutional setting, usually for an extended period of time.

It is difficult to provide an accurate profile of the caregiver because situations can vary so much. One caregiver may provide periodic visits or telephone calls, or arrange for other people to assist in giving required care. Another may provide full-time care for another person and perform a variety of tasks, including shopping, running errands, driving, cleaning, doing laundry, cooking, managing finances, bathing, dressing, securing medical treatment, administering medications, or furnishing hands-on medical care. Sometimes a caregiver will start by providing minimal care to another, and find the care increasing as the person's situation changes.

## RESEARCH FINDINGS ABOUT CAREGIVERS

You may be interested to learn that research findings from the United States Administration on Aging, Department of Health and Human Services indicate:

- \* Most caregiving is informal, unpaid, and provided to a person aged 65 or older with an impairment that affects independence and requires ongoing assistance.
- \* About 80% of all long-term care is provided by family members or friends.
- \* The spouse usually remains the primary caregiver as long as possible, followed by a daughter or daughter-in-law.
- \* Caregivers are usually female, with an average age of 46.



\* Husbands as caregivers are more advanced in age, with 42% older than 75.

- \* Only one in five individuals receiving long-term care lives in a nursing home.
- \* As increasing numbers of men and women join the ranks of the "oldest-old" (85+ years), caregivers themselves are frequently over age 60.
- \* The average time spent caregiving is 18 hours per week.
- \* Intense caregiving takes place in 25% of caregiving households, where care is provided at least 40 hours per week
- \* More than 40% of all caregivers concurrently care for children or youth under age 18.
- \* About two out of three caregivers are employed full or part-time, with one-half reporting that their caregiving responsibilities have had an impact on their ability to work.

# III. LIVING WITH CHANGE

We know that physical and mental changes occur with age. Despite these changes, many older people can continue to function independently. Those who cannot require care from others. Typical illnesses or conditions that create the need for care are: aging, decreased mobility, dementia, heart condition, cancer, stroke, arthritis, diabetes, lung disease, vision loss, mental illness, broken bones, neurological problems, and high blood pressure.

Because of the overall growth in our community's older population, there has been an increase in the number of people needing care, and the provision of assistance to a relative, friend or neighbor is becoming more common. It is likely that the number of caregivers will continue to increase, and many more people can expect to become caregivers at some point during their lifetime.

If you are already a caregiver, you can expect your caregiving situation to change over time because the physical, emotional, or mental health of the person receiving care may change and your own situation may change. As a result, it is important to continue to assess the wants and needs of everyone involved, and to adjust your care as physical, mental, and emotional changes dictate. The following sections may be helpful to caregivers in assessing physical and emotional changes, particularly in older people.

## A. PHYSICAL CHANGES

Expect changes, including the following, to occur as people grow older:

- \* Body functions slow down. Digestion of food, elimination of body waste, speed of messages to and from the brain, heart output, muscle tone and lung function take more time and operate with less efficiency.
- \* Bones become thinner and more brittle, and blood vessels become more fragile, making the older person susceptible to fractures and injuries from even minor falls.
- \* It is often more difficult to resist disease and illness.
- \* The senses decline. Visual acuity usually decreases and there may be difficulty coping with glare, adjusting to fluctuations in light, and distinguishing boundaries of objects. Hearing loss

at high frequencies may occur, prohibiting the individual from understanding conversational exchanges. Taste buds decrease in efficiency, causing foods to be less palatable.

- \* The pain response mechanism is less acute, increasing opportunities to neglect real physical problems.
- \* Balance may become unstable, and/or a tendency to become dizzy may become noticeable.
- \* Regulation of body temperature and adjustment to extremes of heat and cold may become more difficult.
- \* Sleep patterns may alter. Less sleep may be needed, or the individual may sleep at different times of the day or evening.

Most of these conditions can be managed with appropriate treatment. Hearing aids, medication, physical therapy, counseling, glasses, surgery, special equipment, and behavior modification techniques are some of the ways to make a positive difference in quality of life as people age.

Although normal physical changes occur with age, it is critical to know what is normal for the individual in your care. Be aware of sudden or long-term changes in behavior or physical status, and report any new or unusual symptoms to the person's physician. When in doubt it is better to call than wait until a problem worsens or becomes serious. You may want to refer to the following list of physical signs to assist you in discussing the individual's health and mental status with his/her health care professional(s).

## **B.** EMOTIONAL CHANGES

#### PHYSICAL CAUSES

A physical condition may cause emotional and mental changes. Often, what appears to be a deterioration in mental alertness may be caused by reversible medical problems including dehydration, malnutrition, improper medication or dosage, alcohol abuse, infection, hearing loss, or heart disease. (Refer to section IV.B. for more information on physical care, medication, diet and nutrition.) Therefore, an evaluation of the individual's physical health is an important first step in determining the cause of any change in his/her emotional/mental functioning, and properly treating it.

#### WORSENING EMOTIONAL CONDITIONS

In addition, some emotional changes may occur with age, and/or conditions that were present at an earlier life stage may become more noticeable. Be alert for: signs of depression (which may include irritability, changes in mood, diminished interest or pleasure in usual activities, weight loss, insomnia, agitation, fatigue, feelings of worthlessness or guilt, problems with concentration, and recurrent thoughts or discussion of death or suicide); anxiety; alcoholism; increased reliance on medication; anger or aggression; hypochondria (preoccupation or fear that one has a serious disease based on misinterpretation



of symptoms); and delusions or hallucinations (odd or bizarre behavior that results in a belief that imaginary situations, people or things are real.).

#### **EXTREME CHANGES**

Some changes in behavior and personality may be barely perceptible; others may be more extreme, warranting a call to the person's physician. For example, if the person you care for is always outgoing and suddenly becomes withdrawn or unfriendly, that is cause for concern. When the individual spends an undue amount of time complaining about a situation that affects daily living, you may want to contact his/her physician. A good rule of thumb – when in doubt, check it out.

#### PERSONAL LOSSES

It may be helpful to keep in mind that the individual's state of mind and behavior may be influenced by personal losses that are difficult to cope with, including:

- \* Loss of social contacts as old friends die or move away.
- \* Loss of closeness, particularly if a spouse or significant other has died
- \* Loss of roles (as a husband, wife, sister, brother, etc.)
- \* Loss of financial security
- \* Loss of or change in home or apartment
- \* Deterioration in physical health, and
- \* Loss of self-determination, self-respect, self-worth, or self-confidence

How an individual adapts to these losses and to feelings of dependency, anxiety, and fear depends on a variety of factors. The pace of change is important in helping him/her deal with challenges, as are lifelong habits. If the person always coped well with challenges, he/she may continue to do so. The type of resources and supports the individual feels he/she can rely on are important factors in his/her ability to cope. Money, family, friends, and personal strengths are all resources that can help in coping with unwelcome change.

# STAYING EMOTIONALLY HEALTHY

As a caregiver, you may not have control over many of the factors affecting the person in your care, but you can assist him/her to remain mentally and emotionally healthy through different techniques or strategies, such as the following, that encourage the individual to enjoy life and overcome negative behavior patterns.



- If the person becomes overwhelmed by losses or problems, it may help to divide tasks into smaller components.

- A change in activity or physical location may have a positive effect.
- If the individual asks the same questions repeatedly, answer in the same manner each time, using a calm tone of voice. Remaining patient is often difficult, but can become routine with practice.
- Include the person in family and community activities, and ask for his or her opinions and ideas.
- Touch and hold the person when appropriate.
- Encourage participation in social activities and friendships, and help them to develop new ones.



- Remind the person of any special events they may unintentionally forget, and then celebrate them together.

#### ADDITIONAL HELP

Spiritual needs become more important to many people as they age. You may want to talk with your loved one about his/her spiritual needs and explore opportunities in the community to meet these needs, as well as your own. Contacting churches, synagogues, and other places of worship for spiritual counseling and support may be helpful.

Entertainment opportunities are plentiful and can help all of us to continue to enjoy life. Videotapes, a trip to the movies, car rides, large print books or books on tape, and restaurant meals, if appropriate, can be enjoyable for those in your care. Some people particularly enjoy movies and music from the era when they were younger.

Despite your best efforts, the person in your care may have negative behaviors and personality changes that do not improve. Seek professional assistance with emotional problems when they become more extensive than you can handle.

# IV. PROVIDING CARE

To assist caregivers in providing day-to-day care, the next sections provide tips to:

- Establish good listening and communication skills
- Manage daily routines
- Manage contact with physicians and use of medication
- Provide proper diet and nutrition, and
- Maintain a safe environment

## A. <u>LISTENING AND COMMUNICATING</u>

As full-time or part-time caregivers, or concerned family members, friends or neighbors, you are very important in the lives of your loved ones. Your love and support are needed whether you live with the one you take care of, or talk with him/her regularly and frequently, or infrequently. It is helpful to your loved one and to your relationship with him/her to listen carefully as he/she communicates with you.



#### PUT YOURSELF IN HIS/HER PLACE

The purpose of careful listening is to focus closely on the true meaning behind the individual's words. If, for example, your father says, "I probably won't live much longer now," and you respond, "You will live to be one hundred," he may view you as indifferent to the issues that most concern him. He may need to talk about dying, and his comment could be an indirect way of bringing up the subject. In listening, be where the person is; put yourself in his/her place, and ask yourself: "What does he/she really want to talk about?"

#### ENHANCE COMMUNICATION

Other ways to enhance communication are: avoid engaging in arguments; set your own feelings aside; let the individual know that you have heard what he or she has said; talk about the problems and challenges you face; and ask the person for his/her opinion and advice. If the person is homebound, bring the community in by focusing the conversation on the events of your day.

It may be helpful to the person to include touching as part of your communication routine. If you are not normally affectionate, you might try hair brushing, shoulder rubs, or handholding.

It is also helpful to offer reassurance and praise throughout the day. Positive reinforcement is a powerful tool and invariably works better than criticism. It's good to recognize and reward success as often as possible. It's also better to tell the person what he/she needs to do, rather than what he/she should not do.



#### **MAXIMIZE REMINISCING**

You maximize the effectiveness of reminiscing (times when the individual talks about past events), when you consider that talking about the past may be an avenue to moving towards the future, working out the present, preparing for death, or simply recapturing happier times. You may learn from hearing about the person's memories and discover valuable new information. You also can use the conversation as a springboard for discussion of shared experiences. It's often a good idea to keep a

tape/video recorder or journal on hand to record the person's recollections of their early life and experiences. This can be a valuable source of information for children and grandchildren, and the process can promote a feeling of self-worth for the individual.

## **ORIENTATION TO REALITY**

Reality orientation may help a confused person increase his or her mental alertness, and can easily be incorporated into communication during regular activities. For example, you might: remind the individual of the date, time, place and other current facts each morning at breakfast; use a bulletin board to display a calendar, newspaper, or significant pictures; and schedule daily activities at the same time to establish a regular pattern.

# TIPS FOR EFFECTIVE COMMUNICATING AND LISTENING

The following tips may also be helpful in enhancing communication:

- **Set aside** a special time during the day when you can devote your full attention to the individual.
- Choose a quiet place to talk.
- **Speak** clearly and slowly.
- Use short, simple sentences.
- Make certain there is adequate light available.
- **Sit** face to face.
- Make eye contact.
- Adjust your own conversational expectations to meet the person's abilities.
- **Reduce** distractions.
- **Get** the individual's attention, perhaps by using touch or by checking with them while you are talking, to make sure they hear and understand.
- **Repeat** sentences using different words.

#### IF THE INDIVIDUAL IS HEARING IMPAIRED

- Use a calm voice (shouting distorts words and makes speech harder to understand).
- Minimize background noises.
- Use hand signals or pictures instead of words.
- Lower the pitch of your voice (and of the telephone, doorbell, and emergency alarms).

- **Speak** toward the individual's better functioning ear.
- **Keep** your hands away from your mouth.
- **Avoid** eating, chewing, or smoking while talking.
- Use gestures to illustrate content.
- Use short and more concise sentences.

#### IF THE INDIVIDUAL IS VISUALLY IMPAIRED

- **Allow** him/her to take your arm for guidance when you walk together, encouraging a feeling that he/she is in control.
- **Describe** the next step, e.g., "I am giving you your coat."
- Give clear directions, e.g., "We are turning right." "We will be going up two small steps."
- **Speak** in a normal tone of voice.
- **Do not** leave the person without giving him/her a verbal cue that you are leaving, e.g., "I am going to leave now." "I will return in a minute."

# B. MANAGING DAILY ROUTINES

Perhaps the most difficult challenge of caregiving is fitting everything that has to be done into the schedule. Managing many tasks may seem overwhelming and tiring, making it difficult to think clearly and remember everything, particularly if you provide full-time care.

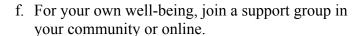
The publication, "And Thou Shalt Honor: A Caregiver's Companion," edited by Beth Witrogen Mcleod, advises caregivers to make a checklist to help manage their many tasks. You may find it helpful to follow these steps:

# 1. CAREGIVER'S CHECKLIST

- a. Write down everything with which your loved one currently requires assistance. Get as much input as possible from your loved one as to items to be included on the list. Determine how often each task must be performed; be as specific as you can.
- b. Gather information about caregiving resources in the community such as Meals on Wheels, transportation services, adult day care and respite care. (See section VII. A. Community Services in Howard County). Contact just one of these to start.
- c. Once you know what various agencies and organizations can offer, go back to your caregiver to-do list (step <u>a.</u> above) and mark which tasks agencies/organizations are able to handle. Keep contact information for everyone you deal with in case you have additional questions. Include name, date spoken

to, costs, and eligibility requirements to receive services.

- d. Plan to share your list and findings with your loved one and family members and friends who make up the caregiving circle. This might best be done at a family meeting.
- e. Hold a family meeting to allow all, perhaps even extended family, friends and neighbors who may be willing to help, to gather to discuss the person's circumstances and needs, and to express opinions about what needs to be done, by when and by whom. Include those out-oftown who can come in periodically or give verbal and/or financial support. If the meeting achieves its purpose, everyone will pull together to support the primary caregiver and ease the physical and emotional demands of care. Remember to keep in touch by e-mail with everyone in the caregiving circle.







# **TIPS for Organizing Tasks**

- \* Organize tasks in a way that is flexible enough to give both the caregiver and the person being cared for personal time.
- \* Create a daily or weekly plan or schedule of what you want to accomplish, but be realistic and make certain you don't include so many activities that you become overworked, overwrought, and overwhelmed.
- \* Establish some continuity by scheduling certain tasks for the same time and/or day of the week. In doing this, experiment and make changes when required.
- \* Remember that it is important to allow plenty of time to get to appointments, complete daily routines, and finish meals. You don't want being late to create undue stress for either you or your loved one.
- \* To the extent possible, use common sense, keeps things simple, and retain a sense of humor.
- \* Keep in mind that if your loved one won't cooperate when you want to do a task, allow a few minutes to elapse and try again. The individual may have forgotten his/her resistance, or been allowed the time to adjust to the request.

## 2. PHYSICAL CARE

#### EMPHASIZE INDEPENDENCE AND DIGNITY

If you provide physical care, include the person receiving the care in performing procedures as often as possible. That helps to stress independence and regard the person as an adult. Be sure to emphasize dignity and respect even if the person's physical and mental functions are diminished. You can do this by: explaining what you will be doing and why, minimizing unnecessary embarrassment, dividing large tasks into smaller steps, providing acceptable and safe choices in meals, clothing, and in the manner tasks will be performed, and delivering positive reinforcement. It's helpful to keep as many past routines as possible.

It's also important to set limits and refuse unreasonable requests, make time for fun and take others up on offers to help. That last item is so important; you may need a break even when you are not aware of it.

It's a good idea to have the individual participate in the process of arranging his/her environment, including color choices and the safe placement of furniture and personal possessions. Set up the space in a way that will help you, too, especially if he/she is bedridden.

#### ADDITIONAL SUGGESTIONS

Listed below are additional suggestions to maximize day-to-day physical care. You may find one or two that you haven't thought of to enhance your caregiving situation.

- \* No smoking in bed unless someone else is nearby.
- \* Use bright, non-glare lighting.
- \* Have a signaling system (using a bell or whistle, for example).
- \* Ensure good ventilation.
- \* Use a night-light.
- \* Have a special box with a key or a safe in which the person can keep special personal items, not accessible to everyone.
- \* Have working smoke alarms on every floor.
- \* Ensure that the person is not left alone if he or she cannot respond to an emergency situation.
- \* Practice bed safety including: placing a furniture item near the bed for support, using a hospital bed that can be raised/lowered, and keeping the bed in a lower position when the caregiver is not at the bedside.
- \* Have a calendar and clock nearby.



- \* Provide a table for water (in a non-breakable container), books, eyeglasses, and medications (unless the person is confused or forgetful).
- \* Provide cheerful decorations and pictures for visual stimulation.
- \* Have soothing music (radio, CD, or cassette), television, books and magazines available.
- \* Limit the number of loose cords and wires and secure with wide tape if obstructing a walking path.
- \* Assemble clothes in the order the person will put them on.
- \* Have non-perishable snacks and drinks accessible in the bedroom area.
- \* Post step-by-step instructions for various procedures for your loved one on the bathroom mirror, or other mirrors, with diagrams, if necessary.
- \* Place familiar objects (furniture, pictures, mementos, decorative items) in the room.

#### **GOOD GROOMING**

Good grooming contributes to a positive self-image, and helps the individual maintain self-esteem. Grooming may include:

- a. **Exercise**. Check with the physician or therapist to determine type and duration.
- b. **Bathing**. Try sponge bathing rectal, genital, underarm and breast areas, if full bathing is difficult or impossible on a routine basis. Soap may dry out skin. Experiment with a mild, non-deodorant variety and fragrance free lotion. If the person likes certain lotions or colognes, use them as appropriate. If skin is dry try applying lotions while skin is still wet (locks in moisture); pat lightly to dry. If "Do you want a bath today?" is unsuccessful, ask "Do you want a bath at 2:00 or 3:00 today?"
- c. **Shampooing** hair. Make certain to remove hearing aids before starting. Gather all supplies necessary in advance. Keep the room warm. Short hair is more readily groomed than long hair, but allow for personal preference. Remember that a trip to the salon or barbershop may be uplifting.
- d. **Foot care**. Circulatory problems or diabetes require professional foot care from a podiatrist. Even nail cutting may need to be performed by the doctor. Consider filing sharp edges and/or a gentle foot rub, if medically permissible. If there are no medical reasons requiring a podiatrist's care, soak feet first before cutting nails.



- e. **Shaving**. A beard can be easier to trim if facial shaving is difficult. If an electric razor is used, the individual may be able to shave, or partly shave, himself for a longer time.
- f. **Back or shoulder rub** (if medically permissible).
- g. **Mouth care**. Include tooth brushing, tongue scraping, rinsing periodically, or mouthwash use. Often an electric toothbrush is easier to use than the regular variety.

There are many helpful and simplified procedures for grooming, lifting, moving, transferring, and positioning the individual while caregiving. Ask the physician to request a home visit from a physical or occupational therapist to obtain specific suggestions on functions the client can perform, maybe using an assertive device. Call upon friends, relatives and others to share their care ideas with you. Check caregiving resources in section VII.

# 3. CONTACTS WITH PHYSICIANS AND MEDICATION USE

#### PARTNER WITH THE DOCTOR AND/OR PHARMACIST

You and the person you care for have the right and responsibility to understand the person's condition, including diagnosis and prognosis, and to participate in all treatment decisions. If you have access to your loved one's health and medication information, you can take an active role in partnering with the doctor and/or pharmacist. You can act as a link between them and the patient, recognizing and reporting any changes and providing information in an emergency.

# PREPARE FOR A VISIT (OFFICE, HOME OR HOSPITAL) TO THE DOCTOR

You can help the individual prepare for an upcoming office visit or house call by allowing plenty of time to get ready, and recording the following information in advance:

- \* The specific complaint
- \* Its duration
- \* When it began
- \* All medication currently taken, including over-the-counter medications, and specifics on dosage and time of day

# TO MAXIMIZE THE PHYSICIAN'S VISIT, IT IS A GOOD IDEA FOR THE CAREGIVER TO:

- \* Bring extra paper or a notebook to record the physician's instructions and comments
- \* Discuss any problems and questions during the appointment; discuss general questions with a physician's receptionist, secretary, or nurse
- \* Include the person in discussions as much as possible
- \* Make sure that the individual doesn't miss important details due to a vision or hearing impairment

- \* Inform the doctor about any limitations the person may have when exchanging information
- \* Accompany him or her to the physician's office and into the examination room, if necessary

# IF A SPECIFIC DISEASE IS AN ISSUE, ASK QUESTIONS ABOUT:

- \* The prognosis
- \* Next steps, including any required surgery
- \* Tests, treatments, or procedures recommended at this time
- \* Future treatments and their duration
- \* Alternative or experimental treatments/procedures
- \* Benefits, risks and side effects of each test, treatment, procedure
- \* Ramifications if test/treatment/procedure is not done
- \* Need for specialist, second or third medical opinions
- \* Home vs. institutional care
- \* Services and supplies needed
- \* Cost, and how much is covered by Medicare or other insurance

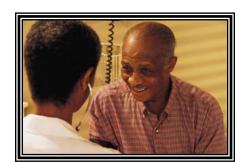
# **EVALUATE THE DOCTOR'S CARE**

As a caregiver, you may be in a position to evaluate the doctor's skills, the care he/she provides, and become an advocate for the person to whom you provide care. Note whether the physician is: talking directly to the person as much as possible, devoting enough time and attention to detail in both initial and follow up visits to get to know the patient well, and is willing to answer questions in a way the caregiver and the patient can understand and not merely dismiss symptoms as "old age." Remember to express gratitude openly to physicians, caseworkers, and others for their assistance and understanding. A "thank you" note, comment, or telephone call can go a long way in boosting the relationship.

#### PRESCRIPTION/NON-PRESCRIPTION DRUGS

Know which prescription and non-prescription drugs the individual takes, so you can discuss them with the doctor and/or pharmacist. Prepare a list of prescription medicines, aspirin, laxatives, vitamins, liquid diets and amounts of alcohol, coffee, and tea consumed (these products might interfere with medicines), and ask about them. In addition, smoking may alter the effects of some drugs (e.g., theophyline is metabolized more quickly in smokers) and, if applicable, you will want to ask about it.





#### CAREGIVERS AND CARE RECIPIENTS SHOULD KNOW:

- The names of all medicines
- The conditions they treat
- How they are supposed to treat the condition
- The side effects or unwanted reactions that might be caused
- When to take medications (with meals, at bedtime, how many times a day, etc.).
- When to refill
- Expiration dates and handling procedures
- What to do if a dose is missed
- Other substances (drugs, vitamins, food) with which the medicine might react.

There are several ways to help the person remain on schedule with prescriptions. One way is to create a daily chart. Other ways include purchasing a weekly medicine dispenser or having the pharmacist put medication in a calendar or easy to dispense packet. You may want to keep a pill splitter handy.

It's important to select a pharmacy that will keep a profile of medications to ensure that different medications may be taken together, and for tax purposes. Ask the pharmacist and/or the doctor any questions about medication issues.

#### 4. DIETS AND NUTRITION

Good nutrition is essential for the maintenance of good health, and it is important for caregivers to understand dietary needs and how to help those in their care to have balanced and varied diets. Here are some tips:

- \* If you prepare the individual's meals, serve foods he/she likes, to the extent possible.
- \* Make certain that dietary needs are met on a daily basis, particularly if special requirements apply.
- \* Check with a registered dietitian, a qualified nutritionist, and/or the physician to determine if a special diet is needed (especially if heart disease, diabetes, ulcers, or colitis are present, or if the person has difficulty swallowing).
- \* Be aware of the fat, fiber, calories and sodium content of foods by checking nutrition information labels on products.
- \* Reduce calories if overweight is an issue. Serving sizes are important, so you may want to check the recommended portion size



\* Also be sure the individual is getting enough water. Remember the body, including the mind, does not function properly without enough water.

# **RECOMMENDED DAILY FOOD SERVINGS**

The U.S. Department of Agriculture's food pyramid shows recommended servings of the different food groups, and a balanced daily diet should include:

- \* Bread, cereals, and grains (5-6 servings), including bread, cooked or dry cereal, rice, or pasta; look for enriched products, and high fiber content
- \* Vegetables (3-5 servings) of fresh/frozen vegetables or juices
- \* Fruits (3-5 servings), including at least one serving of fruit/vegetables high in vitamin C
- \* Milk, yogurt, and cheese (3 servings), preferably low/reduced fat variety
- \* Proteins and meats (2-3 servings), including beans, eggs and nuts
- \* Fats, sweets and oils (used sparingly); avoid saturated fats
- \* At least 6-8 glasses of liquids each day (especially in hot weather) to prevent dehydration



\* Adequate vitamins and minerals are important. A multivitamin once a day is recommended by the Surgeon General.

# OTHER WAYS TO HELP EVEN IF YOU ARE NOT PREPARING MEALS

Invite the individual to a restaurant or home for a special meal.

Give food items as gifts.

Encourage the individual to eat with others at home or at a Howard County senior center.

Arrange for the purchase of home-delivered Meals on Wheels.

Install a microwave oven for simplified heating and meal preparation.

Suggest outings or picnics.

Encourage the individual to obtain quality dental care (ill-fitting dentures or sore gums can affect interest in eating).

Make certain that canned, refrigerated, and frozen foods have not expired.

Create menus together, particularly if a special diet is needed.

Display menus in the kitchen on poster board or newsprint.

Make arrangements with a local firm to deliver groceries.

Encourage the individual to use disposable towels and cleaning cloths.

Buy a cookbook that addresses how to prepare food in small quantities or how to meet special dietary needs.

Note changes in appetite. (Loss of interest in food may signal physical or mental problems.)

#### 5. MAINTAINING A SAFE ENVIRONMENT

To ensure a safe environment for the person in your care, begin by performing a walk-through of the living environment. The list below may assist in recognizing potential problem areas.

# SAFETY CHECKLIST

## **KITCHEN**

Store insecticides, household cleaners, and similar items separately from food.

Place pots on the range to minimize accident potential – turn handles toward the rear and away from heat.

Use plastic and break-resistant glasses and tableware.

Promptly clean water and grease spills.

Equip gas oven with an automatic device to terminate the line if the pilot light is extinguished.

Keep a dry chemical fire extinguisher nearby.

Use potholders (rather than apron or dish towel) to handle hot pots and pans.

Keep range hood grease-free.

Have pot-watcher gadget available to alert the person if foods are boiling over.

Store electrical appliances away from sink or wet areas.

Keep frequently used items on low shelves.

Have kitchen timer readily available, as a reminder that cooked food is ready.

## **BATHROOM**

Clearly mark medicines.

Ensure that shower door is secure and constructed of safety glass.

Store electrical appliances away from bath or shower.

Ensure that shower or bath has non-skid mat, strips, or bath seat/stool to minimize potential for falls.

Affix shower curtain rod to wall with screws.

Install handrails or grab bars in tub or shower and near the commode.

Check the water temperature, or be sure the individual checks it, before he/she enters the bathtub.

Be sure the individual dries self before leaving the tub/shower to minimize potential for falls.

Consider installing an alarm device for emergencies.

# **LIVING ROOM, BEDROOM**

Identify emergency fire exits.

Firmly secure floor coverings (no throw rugs or folds in carpets or rugs).

Have a light switch or lamp beside bed.

Keep a flashlight (with extra batteries) nearby.

Ensure that sufficient ventilation space surrounds television.

Keep traffic areas free of low pieces of furniture.

No smoking in bed.

Keep electrical outlets uncluttered.

Place bed next to wall, or install guardrail that lowers.

Have telephone readily available.

Place answering machine in a convenient location.

## **STAIRS**

Keep stairways well lit with switches at the top and bottom.

Keep stairs free of objects.

Be sure that stair risers are no more than six inches high with adequate foot space on tread.

Be sure there's carpeting and handrails on/by all stairs. (Consider installing railings on both sides).

Berber or low-weave carpet is safer than carpet with higher pile.

Ensure that stairs and handrails are in good repair.

# **BASEMENT**

Store paint thinners, paints, and solvents in original closed containers away from potential ignition sources.

Disconnect appliances and tools when not in use.

Ensure that fuses are proper size for circuits they protect.

Keep basement free of unnecessary clutter.

Regularly check heating/cooling system.

Keep breaker box in good condition with minimal overload potential.

#### **GENERAL**

Install levers in place of doorknobs and other knobs.

Install a light switch by door of each room.

Attach table level switches to bedside lamps.

Use remote light switches, if necessary.

Keep flashlights conveniently located, with extra batteries.

Place list of emergency numbers near telephone.

Install dead bolt or pin-fall locks on entry doors.

Install a peephole or chain on entry door.

Install smoke detectors on each floor (monthly battery checks).

Use chairs that are high and well constructed.

Keep radio with extra batteries in home.

Install grab bars in dressing area.

Keep rock salt or sand to melt icy patches on steps and walkways.

# FALL PREVENTION INFORMATION/ASSESSMENT

The Fall Prevention component of the Howard County Aging in Place Initiative provides direct service and community education and training to consumers and professionals in order to reduce the number of accidental falls. Direct services to seniors at risk may include consultation, in-home assessment and recommendations for a personalized fall-prevention strategy, including environmental modifications, lifestyle improvements, and community referrals. For more information, contact the Maryland Access Point (MAP) of Howard County at 410-313-5980.

# **HOME REPAIR/RETROFITTING**

The Office on Aging Home Repair/Retrofit program provides structural and safety-related repairs to residents' homes, as well as physical modifications to enable residents to occupy their homes in safety and security. Modifications to entries, bathrooms and other main living areas are covered for seniors who meet financial and other eligibility requirements, and persons with disabilities. Call the Maryland Access Point (MAP) of Howard County at 410-313-5980 for more information.

## **OTHER SAFETY/SECURITY ISSUES**

Other safety issues may include wandering, threats to personal safety, crime prevention, driving and economic security.

#### WANDERING

If the individual wanders and it becomes a safety issue, you can put some minimally invasive safety devices in place. Simple inexpensive hotel-type alarms that cost as little as \$10 can be hung from outside doors, or a "chime/alarm" can be easily affixed to a standard door. There are bracelet

security systems that sound an alarm when the individual wanders more than a certain number of feet from the other person wearing the device. Other safety measures include: walkie-talkies if the individual frequently gets lost or confused, gates which can be attached to stairs if they are adequately lighted, an identification bracelet marked with the person's name, medical condition(s), and an emergency contact, especially if the



individual has Alzheimer's disease or another condition that causes forgetfulness or confusion. In addition, consider: moving the person's room away from stairs and/or exit doors, storing "signal" items such as keys out of sight, and redirecting the person's attention if they feel the need to go out at an inappropriate time. Remember that people who have enjoyed walking in the past may need opportunities to walk.

## PERSONAL SAFETY

If you think your personal safety may be at risk, take appropriate precautions such as keeping knives and other potential weapons in a locked cabinet or other safe place, and removing stove knobs if cooking attempts prove hazardous. Physical restraints are a controversial course of last resort, and usually require a physician's consent. It's important to have a telephone and a cellular phone handy in the home for emergencies. Also it's a good idea to plan approaches to an emergency situation in advance, and not to hesitate to call 911, if necessary.

#### **CRIME PREVENTION**

Be aware of crime prevention techniques, including installing light timers, sensors, or remote control units. Encourage the individual in your care to carry small amounts of cash and wear reasonable amounts of expensive jewelry.

#### **DRIVING A CAR**

Driving a car is a major symbol of independence to most people. If the time comes when driving becomes dangerous, you and others in the family and/or caregiving circle will need to ensure that the person stops driving. It's preferable to be honest with the person. Hiding his/her car keys and/or driver's license are extreme measures. If necessary, discuss the problem with the doctor or other professional who may more easily deliver the message. Be ready with transportation solutions, e.g., encourage him/her to try public transportation and other alternatives. Some states, including Maryland, are experimenting with older driver testing programs. Others require a road test at advanced ages. Contact the Maryland Department of Motor Vehicles for more information.

# Make sure the individual who is able to drive safely:

Always wears a seat belt

Has his/her eyesight and hearing tested regularly

Has an automobile that is in good working order

Carries a cellular phone in the car (and understands how to use it)

Avoids driving at night, rush hour, on busy streets, in bad weather, and long distances

Completes the driver improvement course co-sponsored by the American Association of Retired Persons (AARP). This eight-hour classroom course, designed for people 50 and older, is given over a two-day period at Howard County General Hospital's Wellness Center. Call 410-740-7601 for information.

#### **ECONOMIC SECURITY FOR SENIORS**

Seniors often understand physical security better than they understand the modern movement of money and how it may affect their economic security. Caregivers could begin a discussion regarding economic security by stressing the need for it in order to fulfill the seniors' wishes and wants. There are two primary statements to be reviewed on a monthly basis: the checking account statement and the credit card statement. Here a caregiver will find out how money is being spent.

If there are questionable items the caregiver may discuss them with the individual and/or dispute them with the credit card company. Seniors traditionally lose money on: sweepstakes, foreign lotteries, magazine subscriptions, charity scams, and club memberships. Caregivers should be on the lookout for these items. If there are questions, call your local Consumer Affairs office at 410-313-6420.

# V. PLANNING FOR THE UNEXPECTED

## A. HAVE A FAMILY MEETING

Schedule a family meeting when the individual's health is less impaired to talk about the time when he/she will need more care. Invite others, such as friends and neighbors, who may also be in the caregiving circle. Try to keep the atmosphere pleasant and as stress-free as possible. State your issues, as factually as possible, and allow all participants to present their views. Gather information, and begin to make a plan. Identify who will be responsible for carrying out each step of the plan. Everyone should get an assignment. Consider inviting a professional case manager or social worker to help run the meeting if tensions are running high in the family. Plan a follow-up meeting about two months later to evaluate the plan and make any necessary changes. Plan to discuss the following topics:

Division of labor

Stated wishes of the loved one

List of account numbers and institutions for savings and checking accounts, pensions, and other investments

Safe deposit box location, access, and key

Insurance, including health insurance

Advance directives, and powers of attorney for financial and health care

Funeral and burial plans

Social security number, and benefits

Location of important papers

Specific health problems or conditions faced by your loved one to help project future needs

Compensation – decide if the main caregiver will be financially compensated

Determine whose money will be used to pay for services and supports

End the discussion if the parties become tired or quarrelsome and reschedule for another day. Some people may refuse to discuss some or all of the issues. The individual being cared for should retain the right to make his/her own decisions, however uninformed or ill advised, as long as they

are not a threat to safety. You may have to accept the situation even though you believe he/she is making a mistake. You may need to intervene if the person being cared for is at risk.

# **B.** IMPORTANT DOCUMENTS

As a caregiver, you need to know whether a will, durable power of attorney for asset management, and advance directives relating to health care have been prepared for your loved one, and where they are kept. If they have not been prepared, you may want to discuss these documents with the individual. For more information, contact an attorney knowledgeable about such matters and/or request a copy of "Advance Directives – A Guide to Maryland Law on Health Care Decisions" (which includes forms) from Library and Information Division, Department of Legislative Reference, 90 State Circle, Annapolis, Maryland, 410-841-3810/3886, Maryland Relay 711. Be aware that Hospice, if involved, may be able to secure Advance Directives planning assistance

# **WILLS**

It is important for every adult to have a will, outlining how the person wants possessions and money distributed when he/she dies. While a person can write his/her own will, it is recommended that this important document be drafted with the help of an attorney. Be sure that the caregiver and other family members know that a will has been made, and where it is kept.

## DURABLE POWER OF ATTORNEY FOR ASSET MANAGEMENT

This document names an agent to handle the person's financial affairs. The document can appoint someone to handle the person's affairs while he/she is still competent. Unless the document specifies that it will only be effective while the person is competent, the document will remain effective if and when the person becomes incompetent.

## **ADVANCE DIRECTIVES**

Advance directives are legal documents that allow an individual to specify exactly what type of medical care should be administered if he/she is unable to make his/her own medical decisions. It allows the individual to dictate exactly whom he/she wants to make these care decisions on his/her behalf – be it caregiver, friend, or family member. Advance directives include living wills and health care proxies. Both are necessary to ensure that the person's wishes are respected at the time of incapacity.

# **LIVING WILL**

A living will (not to be confused with the type of will where you leave your possessions to someone else) provides an individual the opportunity to officially state the types of care he/she would, or would not, want if facing terminal illness and could not communicate his/her desires to the doctor. Living wills are often used to outline specific treatments that are not wanted in order to sustain life (such as life support). Living wills can dictate the life sustaining medical procedures the person wants administered on his/her behalf. You obtain a Living Will form at most hospitals, but the laws governing living wills can vary from state to state, so it is important to consult a professional who has expertise in this legal area before creating a living will you wish to use in another state.

## **HEALTH CARE PROXY**

The purpose of a health care proxy, also known as a Durable Power of Attorney for Health Care, is to enable an individual to legally name a family member or friend who would need to make decisions for him/her if he/she could not make his/her own decisions when medical circumstances create needs that have gone beyond the directions of a living will. A health care proxy also provides a list of the powers granted to the person, as well as a list of specific situations and decisions that can be made on another's behalf.

## **ORAL DIRECTIVE**

Competent individuals can orally appoint a health care agent and/or give instructions about medical treatment. The oral directive must be made in the presence of the attending physician and a witness, documented in the medical record, and signed and dated by both the attending physician and the witness.

# **Important Considerations with Advance Directives**

# Make sure you:

Understand your state's regulations for living wills and health care proxies

Discuss advance directive issues with the person's doctor, and provide copies of these documents to be kept with the patient's records

Include copies of directives with the person's medical records

Keep the documents updated whenever the person's wishes or needs change

Discuss advance directives with family members so they clearly understand the person's wishes

Give a copy of the directives to anyone who would be contacted if the person were hospitalized

Be certain to bring them if admission to a hospital or other medical facility is indicated

# EMERGENCY MEDICAL SERVICES PALLIATIVE CARE/DO NOT RESUSCITATE ORDER

Although advance directives serve patients well in clinical environments, they can pose practical problems in life-threatening situations when emergency medical services are necessary. Emergency personnel are required to evaluate the situation and take appropriate action (including life-saving measures) when summoned to the scene of a medical crisis. The Maryland "Emergency Medical Services Palliative Care/Do Not Resuscitate" program was developed in 1995 as a result of the need to allow emergency medical services personnel to honor the patient's wishes in an emergency. To obtain an Emergency Medical Services/Do Not Resuscitate order, you must speak directly to the individual's physician, who can provide you with further information and the required forms.

# VI. DEVELOPING SUPPORT SYSTEMS

## A. DEALING WITH CAREGIVER STRESS

As we noted earlier, caregiving can be taxing emotionally and physically, and there are so many aspects of it that can cause stress. For this reason, it is essential for caregivers to have support systems to help in stress management, and to enhance the caregiving situation.

#### **STRESSORS**

Certainly, it is stressful to be removed from your usual roles and thrust into an unfamiliar caregiving situation. Perhaps you are grieving for the losses you face as a caregiver, including loss of income, vacation, travel or personal time, talks with friends, hobbies, privacy, sex, etc.

It is also important to recognize that when you are caring for someone, changes in the person's physical, mental and emotional status can affect your relationship with him/her, and cause stress. For example, increasing demands from the person you care for are likely to be stressful. Even if the person's behaviors are unintentional, it may be difficult not to view them as offensive or disturbing, and not to take them personally. During the course of providing care, you may feel that the person is deliberately attempting to control you, perhaps by creating feelings of guilt, or using imagined illness to gain sympathy. It is difficult to believe that the illness limits the person's judgment, and that controlling behaviors are beyond his/her capacity.

#### **UNCOMFORTABLE THOUGHTS**

As the relationship becomes less manageable, you may experience uncomfortable thoughts and emotions, such as:

Someone else is in control of my life.

Nothing I do is enough, and I feel guilty about it.

I can't do this; I'm not strong enough.

Don't I have the right to a life, too?

Everything I do seems to be too much and I am angry and frustrated.

I'll take care of myself, if there is time at the end of the day.

I am alone in the world; nobody cares; all the responsibility is on my shoulders.

I am grieving for the loss of the person I knew.

This new person, who is not what he/she used to be, embarrasses me.

I can't cope with my own fears of aging and loss.



This isn't what I expected at this time of my life.

There is not enough time in the day to meet everyone's needs.

I'm overwhelmed and burned out.

I wish the person would hurry up and die.

I can't keep this up much longer.

I should not be having these feelings; I'm ashamed and guilty about it.

#### **MANAGING STRESS**

Feelings and thoughts similar to those listed above are normal, and you do not need to feel guilty about experiencing them. If you view such feelings and thoughts as indicators of stress, you may be able to step back for a moment, assess your situation and find ways to cope better. You owe it to yourself and to the person in your care to manage your stress and your feelings. Think of the airline instruction that is familiar to anyone who flies, "In the event oxygen is needed, put on your own mask before assisting children or others." The meaning behind that instruction is that you'll be unable to help another if you neglect yourself.

Because the responsibility, emotion and stress of caregiving put you at risk of exhaustion and illness, you must continue to perform self-assessment to determine how you're managing. If you develop sadness, crying, appetite and sleep disturbance, irritability, physical problems (especially of the stomach or back), thoughts of wanting to die, or wanting to hurt the one you care for, you may be depressed. Depression, a physical illness, occurs in many caregivers and can limit your ability to help yourself and others. There are excellent treatments including medication and therapy that can help you rebalance and resume healthy caregiving.

On an ongoing basis, you will also need to take appropriate steps to ensure that you are caring for yourself and not becoming exhausted. Caregiver "burnout" is common, and you want to avoid it. Here are some tips that may be helpful:

# B. TIPS FOR SELF-CARE AND STRESS MANAGEMENT

Take regular breaks, at least 15 minutes a day.

Vent your feelings by talking with someone you trust, e.g., a spouse, friend, member of the clergy or professional. Crying may provide a welcome release.

Allow family members and others to care for your loved one, so you can take time for yourself and participate in activities you enjoy.

Relax your body through exercise, petting a cat



or dog, yoga, gardening, swimming, and snoozing.

Ease your mind by laughing with a friend, at a funny television show, magazine or book, listening to music, dancing, meditating, praying, doodling or drawing.

Pamper yourself by having a massage, manicure or pedicure, dinner out, soaking in the tub, enjoying flowers, tea, or aromatic candles.

Join or start a support group. Support groups can be found through a number of sources, including other caregivers, local chapters for disease-specific organizations, adult day care, caregiver organizations, local faith organizations, the Office on Aging, and online.

Make sure your role is well defined and that communication is clear among all participants in the caregiving circle. Each involved person needs regular reports on the caregiving situation. Computers/telephone calls can make this possible.

Use caller ID or an answering machine to screen calls and allow rest periods.

Talk about end-of-life decisions with the person you're caring for; get forms completed and posted if they do not want to be resuscitated.

Make action plans with achievable goals. Include what you will do, how much, when, and how often.

Say "no" to unreasonable demands.

Ask for and receive help before the situation spins out of control. Is there any activity you dislike that can be eliminated or performed by someone else? Who else can assist you? What are the pros and cons for each alternative?

If you find it necessary to consider outside placement or change the location of the caregiver situation, try to keep guilt feelings under control and focus on the problemsolving aspects.



If you have a job, discuss the caregiving situation with your employer. The Family and Medical Leave Act (FMLA) may protect your job during an absence of several months per year. Perhaps your employer will extend you the courtesy of a flexible schedule, jobsharing, or allow you to work at home using phone, fax, and Internet services.

Avoid high calorie foods; substitute healthy fruits, vegetables, and calcium-rich protein snacks.

If necessary, secure additional help from professional sources. Community agencies may be able to provide assistance with physical tasks or counseling if you feel overwhelmed by the caregiving situation. You may want to talk with your family doctor, or another health professional about getting counseling.

You may want to identify or engage an attorney who can help you and the individual with complex issues, decisions, and other arrangements.

If you reach the point where stress management techniques and counseling are not enough to make the situation manageable for you and your loved one, you may decide that it is time to give up the role of full-time caregiver. It is very difficult to be a full-time caregiver for an extended period of time, and it is also very difficult to give up the caregiver role. As a last resort, you may need to consider other alternatives, including placing your loved one in a nursing home, small group home, or assisted living community. Although making these changes may be extremely difficult, new arrangements may be the right thing to do for your loved one, and for yourself.

# C. PLACING YOUR LOVED ONE IN A NURSING HOME

Placing your loved one in a nursing home is one of the most difficult decisions a caregiver may face. Many people are unaware that there may be choices other than nursing home placement. Before you make arrangements for nursing home placement, call the Maryland Access Point (MAP) of Howard County at 410-313-5980 to explore options for in-home services or alternative living situations. The goal is to help people be safe and as independent as possible in the least restrictive setting. Use the Eldercare Locator at 1-800-677-1116 and/or <a href="www.aoa.dhhs.gov">www.aoa.dhhs.gov</a> to find similar programs in other parts of the United States.

When your loved one is in a nursing home, your role as a caregiver has changed but it has not ended. Positive, frequent contact with family and friends will help the person adjust to life in the nursing home, and will also help to ensure that he/she receives the best possible care. Once your loved one's physical care and activities of daily living are being provided via professionals, you can develop or reestablish your relationship on another caring level. You can be a friend, adult child, wife/husband again.



# VII. <u>RESOURCES</u>

# A. <u>COMMUNITY SERVICES IN HOWARD COUNTY</u>

There are many support services available for senior citizens and others requiring care, and/or their caregivers. Below is a list, by category, of Howard County services that may be helpful to you in your role as caregiver. For more information call the Maryland Access Point (MAP) of Howard County at 410-313-5980, Maryland Relay-711. Ask for a copy of the Senior Resource Guide 2007-2008 (or future editions), a comprehensive annual information directory for senior citizens that includes discount information, housing listings, and many other resources. You may

also want the brochure entitled "Services for Seniors," which summarizes the services of the Howard County Office on Aging. In addition, the Office of Citizen Services, in the Office on Aging, publishes its "Human Services Guide," available by calling 410-313-6400. Please ask about publications in other languages.

# 1. INFORMATION

# MARYLAND ACCESS POINT (MAP) OF HOWARD COUNTY

This service of the Howard County Office on Aging is a one-stop center for information and benefits for older persons. This office also assists in screening for services, and makes referrals to other agencies. Telephone: 410-313-5980, email: <a href="map@howardcountymd.gov">map@howardcountymd.gov</a>

# SENIOR HEALTH INSURANCE ASSISTANCE PROGRAM (SHIP)

SHIP, a service of the Howard County Office on Aging, provides assistance with health insurance issues, including Medicare supplements, long-term care insurance, prescription drug resources, and more. Call 410-313-7392.

#### TRAINING FOR CAREGIVERS

Family and Children's Services of Central Maryland has received a grant from the Horizon Foundation to provide professional training in the home for caregivers in Howard County. The training will consist of hands-on instruction by a registered nurse to family members or friends who are the primary caregivers. Call 410-997-3557, extension 243.

#### ELDER CARE LOCATOR

This service provides information about community services for older people anywhere in the United States and its territories. Call 1-800-677-1116, or visit the web site at www.aoa.dhhs.gov.

#### **DISABILITIES SERVICES**

This organization, under Howard County's Department of Citizen Services, provides information about community resources to persons with disabilities, their families and service providers. Call 410-313-6402.

#### CHILD CARE RESOURCE CENTER

This organization, under Howard County's Department of Citizen Services, provides information, training and expert advice to parents, childcare professionals, and employers. "Relatives as Parents" (RAP) provides support to kinship caregivers who are raising children whose parents are unable or unwilling to care for them. For more information, call 410-313-1940.

#### THE ARC OF HOWARD COUNTY

This organization provides comprehensive services for the developmentally disabled. Call 410-730-0638.

#### HORIZONHELP

This project of the Horizon Foundation is a web-based information and referral service to assist Howard County residents in finding programs and services. Website: <a href="www.horizonhelp.org">www.horizonhelp.org</a>.

# FOREIGN-BORN INFORMATION AND REFERRAL NETWORK (FIRN)

This non-profit organization provides information to immigrants who live or work in Howard County. Their HELPBOOK in Korean, Spanish and French are available and can be obtained by calling 410-992-1923.

# 2. <u>ASSESSMENTS AND EVALUATION</u>

# ADULT COMMUNITY EVALUATION SERVICES (ACES)

ACES offers professional no-fee assessment services for adults who may need assistance to remain in a community setting. Services include: telephone consultation, screening, referral and multi-disciplinary evaluations. ACES is a cooperative program of the Howard County Department of Social Services, the Howard County Office on Aging, the Maryland State Department of Health and Mental Hygiene, and the Howard County Health Department. The client, a family member, friend, professional, or other concerned individual can make referrals. Call the Maryland Access Point (MAP) of Howard County at 410-313-5980.

# 3. <u>CASE MANAGEMENT/COUNSELING</u>

#### **CASE MANAGEMENT**

Case management includes assessment, assistance with procuring services, and on-going involvement to ascertain that a care plan remains appropriate. It's available free of charge from the Office on Aging for those in the Older Adult Medicaid Waiver program or receiving Senior Care services

Private case managers/agencies also provide these services. Charges are about \$300 for an initial assessment with \$50-\$100 per hour for continuing services.

#### **COUNSELING**

Individual, family, and group counseling/assistance in coping with a variety of problems is available from public and private sources on a full pay, sliding scale or no-fee basis. Specialized counseling is available for individuals and families faced with serious situations such as life-threatening illness or death, or those experiencing problems with drug and/or alcohol abuse.

#### **DISCHARGE PLANNING**

This service is available through hospital and nursing home social work departments. A social worker helps the patient/family/physician to identify appropriate services necessary to support the patient after discharge. Make contact for this service as soon as the family member is admitted to an institution.

#### **OLDER ADULT MEDICAID WAIVER**

This Waiver program, operated by the Maryland Department of Aging, allows services that are typically covered by Medicaid only in a long-term care facility, such as personal care, respite care and other essential assistance, to be provided to eligible persons in their own homes or in assisted living facilities. Individuals 50 and older who meet Medicaid eligibility rules may be able to obtain these services. Additional medical, financial, and technical eligibility requirements may apply. Call the Maryland Access Point (MAP) of Howard County at 410-313-5980.

## LIVING AT HOME: MARYLAND COMMUNITY CHOICES MEDICAID WAIVER

This is a Maryland statewide program that may provide funding for community services and supports to enable adults with disabilities, aged 21-59, who meet Medicaid financial, medical and technical eligibility requirements to live in their own homes. For information, call the Maryland Access Point (MAP) of Howard County at 410-313-5980.

# 4. RECREATION AND OTHER SERVICES FOR SENIORS

## **SENIOR CENTERS**

There are twelve senior centers in Howard County that offer a variety of programs, including informational and exercise classes, travel, meals, entertainment, volunteer opportunities, and socialization. Three sites are designated as Senior Center Plus sites: Western Howard County, Owen Brown, and Ellicott City. There is also a Saturday Senior-Plus Program at the East Columbia Library. The Senior Center Plus locations offer a higher level of services for seniors who need more intense supervision and are limited to twenty participants each. There is usually a waiting list, so contact the center immediately if you anticipate a potential need for services. Listed below are the names and phone numbers for the centers. For Senior Center and Senior Center Plus addresses and hours, refer to the "Senior Resources" directory.

## THE SENIOR CENTERS ARE:

i.	East Columbia 50+ Center, Telephone:	410-313-7680
ii.	Elkridge Senior Center, Telephone:	410-313-5192
iii.	Ellicott City Senior Center, Telephone:	410-313-1400
iv.	Bain Senior Center, Telephone:	410-313-7213
V.	Guilford Senior Center, Telephone:	410-880-5862
vi.	Longwood Senior Center, Telephone:	410-313-7217
vii.	Savage Senior Center, Telephone:	410-880-5915
/111.	Glenwood 50+ Center, Telephone:	410-313-5440

#### THE SENIOR CENTERS PLUS ARE:

1.	Ellicott City Senior Center Plus, Telephone:	410-313-1425
2.	Owen Brown Senior Center, Plus Telephone:	410-313-7218
3.	Glenwood Senior Center Plus, Telephone:	410-313-5442
4.	Saturday Plus Program, Telephone:	410-313-7691

#### ADULT DAY CARE

This program provides a medically supervised day environment where health impaired older adults participate in an organized therapeutic program. Transportation and meals are provided. Fees are based on a private pay, sliding scale, or subsidized basis, including Medical Assistance. Refer to the Senior Resources directory for adult day care listings.

#### RECREATION

A variety of activities, classes, and trips are offered at the senior centers. The Howard County Department of Recreation and Parks sponsors others. A schedule of programs is published regularly in the "Generations/Senior Connection" monthly newsletter of the Office on Aging, and in the quarterly Recreation and Parks catalog.

#### **VOLUNTEER SERVICES**

Homebound support, a service provided by the Office on Aging, offers the following volunteer services, as available, to seniors confined to the home environment. Call 410-313-1417.

- \* Friendly visitor home visits for companionship
- \* Telecheck daily calls for friendly visiting via telephone

#### LIBRARY SERVICES

Homebound residents may apply to have library materials delivered to their homes. Call 410-313-7858. Volunteers from the Howard County library will deliver "Talking Books" (books on tape) and large print books.

Maryland State Library for the Blind and Physically Handicapped lends books in Braille, recorded on discs and cassettes, and in large type, free of charge. Applications for service are available at local libraries or by calling 410-230-2424; TTY-711.

## 5. FINANCIAL SUPPORT

Support is available through income supplements, food stamps and medical assistance. Limited grant funding may be available for: purchasing medications or in-home services, paying energy bills, home weatherization protection for eligible persons, respite care, and other assistance. Contact the Maryland Access Point (MAP) of Howard County at 410-313-5980.

#### 6. HOUSING

#### Refer to Senior Resources for housing listings by category.

**ACTIVE ADULT COMMUNITIES** – Age restricted communities offering a variety of housing styles, including condominiums, townhouses and single family attached and detached units. Facilities are built incorporating the concept of universal design. These communities provide no personal services.

**INDEPENDENT APARTMENTS** – Howard County has subsidized apartment communities providing housing to senior citizens and those with disabilities. There are also moderately priced senior apartment communities. No personal services are provided by these facilities.

ASSISTED LIVING – Facilities that provide assistance with activities of daily living. These facilities are classified as small (1 to 16 beds) and large (16 beds and over). Individualized care plans are developed to meet the needs of residents. Funding is available to eligible individuals through a limited State Subsidy Program and the Home and Community Based Waiver for Older Adults. Payments can only be made to facilities that have been certified as Subsidy and Waiver Providers.

**CONTINUING CARE RETIREMENT COMMUNITIES** – Facilities providing a continuum of care including independent living, assisted living and nursing home as needed to meet the changing needs of the residents. Most require an entry fee, as well as a monthly fee based on services provided.

**NURSING HOMES** – Facilities that provide 24-hour nursing care. Limited Medicare funding is available when skilled services are needed. Medicaid funding is available for long-term care for qualified individuals.

# 7. SPECIAL INTEREST AND SUPPORT GROUPS

A variety of groups meet regularly throughout Howard County to provide support and information to individuals, families, and caregivers. Available support groups include those for Alzheimer's, caregivers and stroke club. For more information, contact the Maryland Access Point (MAP) of Howard County at 410-313-5980 and/or refer to the Senior Resources Guide.

## 8. IN-HOME SERVICES

**HOMECARE REGISTRY** – a list of providers is available from the Howard County Office on Aging. Companion care, housekeeping, personal care, and/or respite care are provided on a private pay basis. Call the Maryland Access Point (MAP) of Howard County, at 410-313-5980.

**HOMEMAKER, PERSONAL CARE, AND NURSING SERVICES** – in home care is available on a private pay, sliding scale or no-fee basis through public or private community agencies.

## 9. LEGAL SERVICES

Services are provided free of charge or on a sliding scale basis to eligible senior citizens. Call the Maryland Access Point (MAP) of Howard County at 410-313-5980.

## 10. MEAL SERVICES

**SENIOR CENTERS AND SENIOR CENTERS PLUS** – lunch and social activities are provided at locations throughout Howard County up to five days per week. Transportation, if necessary, is provided for a nominal fee. Meal fee is on a donation basis. Call Senior Centers for more information.

**MEALS ON WHEELS** – hot lunch and cold dinner are delivered to the convalescent, handicapped, and/or homebound on a sliding fee basis. Call 410-730-9476.

#### 11. TRANSPORTATION

**Howard Transit** – a non-profit agency, provides rides to medical appointments, senior centers, and recreational activities. Vehicles are handicapped accessible with fees on a per-ride basis. Other transportation is provided by volunteer organizations. Call the Maryland Access Point of Howard County (MAP) at 410-313-5980.

The Baltimore Metropolitan Council publishes the "Out and About Travel Guide" which lists transportation providers that offer a range of services, and includes public, private and medical assistance transportation providers in a number of Maryland counties, including Howard County. The Guide is free on the website: <a href="www.baltometro.org">www.baltometro.org</a>. Printed copies can be purchased by calling 410-732-0500.

## 12. OTHER SERVICES

Refer to the Senior Resources directory for information about other services including:

**PERSONAL EMERGENCY RESPONSE SYSTEMS** are mechanical devices that allow someone to call for immediate help very simply. There are charges for the device, its installation, and monthly monitoring.

**HOSPICE CARE** provides comprehensive care for a person with a terminal illness, delivered in the home or in a specialized facility.

**EQUIPMENT/ASSISTIVE DEVICES** – walkers, stair gliders, wheelchairs, toilet lifts, and special utensils can be borrowed, rented or purchased from community groups or private companies. The cost of evaluations and/or equipment may be covered in part/full by Medicare/ Medicaid/other health insurance.

## 13. COMMUNITY OUTREACH

**CAREGIVER EDUCATION** – a service of the Howard County, Maryland, Office on Aging that assists in locating resources/publications for family caregivers, and/or making referrals to appropriate agency and community resources. Contact the Maryland Access Point (MAP) of Howard County at 410-313-5980. Web site: <a href="www.howardcountymd.gov">www.howardcountymd.gov</a>.

# **B. ADDITIONAL RESOURCES**

There are many organizations, disease-specific and others, that you may wish to contact. The following organizations are only some of those that may be helpful to caregivers:

#### **DISEASE-SPECIFIC ORGANIZATIONS**

Alzheimer's Association, Baltimore/Central Maryland Chapter (410) 561-9099; <a href="https://www.alz.org">www.alz.org</a> 24/7 Help-Line: 1-800-272-3900.

American Cancer Society 1-800-227-2345; www.cancer.org

American Diabetes Association of Maryland, 1-800-342-2383; www.diabetes.org

American Heart Association; 1-800-242-8721; www.americanheart.org

American Lung Association; 1-800-586-4872; www.marylandlung.org

American Parkinson Disease Association; 1-800-223-2732; www.apdaparkinson.org

American Stroke Association; 1-800-242-8721; www.strokeassociation.org

Arthritis Foundation; 410-654-6570; www.arthritis.org

National Kidney Foundation of Maryland; 1-800-671-5369; www.kidneymd.org

National Parkinson Foundation; 1-800-327-4545; www.parkinson.org

National Institutes of Health, National Institute on Aging, Alzheimer's Disease Education and Referral Center; 1-800-438-4380; www.nia.nih.gov

## **OTHER ORGANIZATIONS**

American Association for Retired Persons (AARP); 202-434-2277; www.aarp.org

Children of Aging Parents; 1-800-227-7294; <a href="www.caps4caregivers.org">www.caps4caregivers.org</a>

Federal Website of Disability-Related Government Resources; www.disabilityinfo.gov

Howard County Department of Citizen Services: <a href="www.howardcountymd.gov">www.howardcountymd.gov</a>
Office of Consumer Affairs; 410-313-6420; Disabilities Services; 410-313-6402; Office on Aging; 410-313-6410

Howard County Department of Social Services; 410-872-8700; www.dhr.state.md.us

Jewish Family Services; 410-730-4976 x25; www.jewishhowardcounty.org

Legal Aid Bureau, Inc./Metropolitan Maryland Office; 410-480-1057; www.mdlab.org

Easter Seals Home and Community Therapy (Occupational, Physical and Low-Vision Therapies); 1-800-221-6827; <a href="https://www.easterseals.com">www.easterseals.com</a>

Maryland Department of Aging; 1-800-243-3425; www.mdoa.state.md.us

Medicare; 1-800-Medicare; www.Medicare.gov

National Family Caregivers Association (Kensington MD); 1-800-896-3650; <a href="https://www.nfcacares.org">www.nfcacares.org</a> (Call for Caregiver's Support Kit).

National Alliance for Caregiving (Bethesda MD); 301-788-8444; www.caregiving.org

National Caregiving Foundation (Alexandria VA); 1-800-930-1357; www.caregivingfoundation.org

Family Caregiver Alliance (San Francisco CA); 1-800-445-8106; www.caregiver.org

Service Coordination of Howard County; 410-772-8774

Social Security Administration; 1-800-772-1213; www.ssa.gov

Department of Veteran's Affairs; 1-800-827-1000; www.va.gov

Well Spouse Foundation; 1-800-838-0879; www.wellspouse.org

# VIII. READING ABOUT CAREGIVING

#### **BOOKS**

There are hundreds of books that discuss various topics related to caregiving. For a sample, explore web booksellers on the internet under the keyword "caregiver." Check the catalog at any of the Howard County libraries to see what books are readily available. Here are a few of the books you may want to read:

Carter, Rosalynn. <u>Helping Yourself Help Others: A Book for Caregivers</u>. New York, NY: Random House.

Mace, Nancy L., et al. <u>The 36-Hour Day; A Guide to Caring for Persons With Alzheimer's Disease</u>, <u>Related Dementing Illnesses and Memory Loss in Later Life</u>, 1994.

Marosy, John Paul. <u>Elder Care</u>; A <u>Six-Step Guide to Balancing Work and Family</u>. 2003. Available from Bringing Elder Care Home Publishing on line at: <u>www.bringingeldercarehome.com</u> or by calling 508-854-0431.

Mayeroff, Milton. On Caring. Harper Perennial Library, 1990.

McLeod, Beth Witrogen. <u>Caregiving: The Spiritual Journey of Love, Loss, and Renewal</u>. John Wiley & Sons, 1999.

Morris, Virginia. How to Care for Aging Parents. New York, NY: Workman Publishing, 1996

Schmall, Vicki L., Ph.D., et al. <u>The Caregiver Helpbook, Powerful Tools for Caregiving.</u> Portland, Oregon: Legacy Caregiver Services. 2000.

Stearns, Dr. Ann Kaiser. Living Through Personal Crisis. New York, NY: Ballantine Books, 1985.

Williams, G.B. and P. Kay. <u>The Caregiver's Manual: A Guide to Helping the Elderly and Infirm.</u> New York, NY: Citadel Press, 1995.

#### **PAMPHLETS**

The following pamphlets about caregiving may be helpful. They can be obtained from Journeyworks Publishing, P.O. Box 8466, Santa Cruz, CA 95061; Phone; 1-831-423-1400; <a href="https://www.journeyworks.com">www.journeyworks.com</a>. Click on "Alzheimer's Disease" to get the titles in the Caregivers Pamphlet Series. There is no charge for sample pamphlets (one of each).

Caring for a Person with Memory Loss and Confusion

Dealing with Anger

**Dealing with Wandering** 

**Experienced Caregivers** 

**Keys to Better Communication** 

Making Bathing and Personal Care Easier

New Caregivers

Social Service and Health Professionals

Tips for a Better Night's Sleep

# IX. EMERGENCY PROCEDURES

We have adapted the following chart on Emergency Procedures from one that was developed by the National Caregiving Foundation. If you use the chart, it is important to keep the information up to date.

## **EMERGENCY PROCEDURES**

#### **CARE-RECIPIENT**

Name	
Nickname	
Address	
Phone #	
Date of Birth	
Social Security #	

Disease/illness/condition						
Blood type	Blood type					
Other						
CAREGIVER						
Name						
Address						
Home Phone	Work Phone					
Other						
EMERGENCY PHONE NUMBER	RS OTHER THAN 911					
Police						
Ambulance						
OTHER						
OTHER						
DOCTOR(S)						
Name						
Address						
Office Phone	Home Phone					
Name						
Address						

Office Phone	·	Home Phone			
SPOUSE, SIGNIF	TICANT OTHER, RELATIVE,	FRIEND, OR NEIGHBOR			
		,			
Relationship	to Care Recipient				
		Home Phone			
Name					
		Home Phone			
PHARMACY					
Name					
Phone #					
Hours					
Medication(s)	Medication(s)				
Medication(s)	Medication(s) producing allergic reaction				
Allergies					
Special Instru	actions				
HEALTH INSUR	ANCE COMPANY				
Name					

	Phone #
	Medicare ID #
FUNI	ERAL ARRANGEMENTS
ANY	ADDITIONAL INFORMATION
	<u>NOTES</u>
